

**AREA OF EMPHASIS:**

# Behavioral and Social Science

## SCIENTIFIC ISSUES

Behavioral and social science approaches are essential in developing knowledge about HIV acquisition and transmission, as well as interventions to reduce risk. In addition, behavioral and social science findings provide guidance to improve the lives of persons affected by HIV/AIDS. Although the means of HIV transmission, i.e., through sexual, parenteral, and mother-to-child routes, have long been identified, a greater understanding of the contexts in which these behaviors occur, their determinants, and effective prevention methods continues to be needed. Surveillance and epidemiologic studies indicate that the epidemic continues to spread in both domestic and international settings. Reports of increases in risk behaviors and incidence of sexually transmitted infections (STIs) among men who have sex with men (MSM), coupled with reports of high levels of seroprevalence among this population in major urban areas, indicate the need for continued research on sexual behavior change. Injecting drug use appears responsible for high seroincidence in several areas of the world, and the desperate poverty of many women throughout the world greatly restricts their options for protecting themselves from heterosexual spread of HIV or for protecting their children from mother-to-child transmission (MTCT). For those who are already living with HIV disease, there are issues of quality of life, access to and utilization of services, effects of stigma and discrimination, and coping with comorbid conditions that behavioral and social science can help address. In considering both prevention and treatment programs, racial and ethnic minorities, women, and disenfranchised groups continue to suffer disproportionately from inadequate access to resources and a dearth of programs responsive to their situations.

The NIH priorities for research reflect the growing emphasis on understanding behavior as multiply determined by factors at many levels. Individuals act to protect themselves from risk or to place themselves at risk not only because of their own needs, skills, motivations, and beliefs, but as these are shaped by the context of relationships, societies, and physical environments in which they find themselves. This broader context includes considerable progress in the biomedical treatment of HIV/AIDS, which brings not only hope for longer life and improved quality of life but also concerns about attendant increases in risk of transmission. The context also includes hope for vaccines and microbicidal products that will aid prevention, and behavioral and social science must be poised to address both the risk-reducing and potentially risk-enhancing aspects of these products.

Because HIV-related behaviors, like all complex behaviors, are multiply determined, NIH research recognizes that no single approach to behavior change is going to be fully effective, much less so considering the varying populations that must be addressed. Therefore, the priorities call for greater involvement of all areas of behavioral and social science in identifying the contributions each can make, and the priorities call for greater integration of behavioral and social science with biomedical research. Further, because it is reasonable to believe that HIV-related behaviors are governed by the same general principles that govern other behaviors, the priorities call for greater leveraging of existing knowledge about behavioral principles to apply and test conclusions developed outside the field of HIV/AIDS research to addressing pressing problems of HIV/AIDS. These priorities are given equal weight and each is considered essential for moving the field forward.

## UNDERSTANDING HIV TRANSMISSION AND ACQUISITION

### PRIORITIES FOR FUTURE RESEARCH:

- **Develop and test the predictive utility of comprehensive models for risk of HIV transmission and acquisition that reflect the complex, multidetermined nature of sexual behavior and the influences that factors distal from the immediate risk behavior have on HIV transmission and acquisition.**
- **Elucidate new and changing patterns, contexts, and kinds of drug and alcohol use and their implications for HIV transmission and acquisition, either directly or as mediators of sexual behavior.**

In order to develop innovative approaches to intervening to prevent HIV transmission and acquisition, more complete conceptual and quantitative models are needed. Better understanding of the factors affecting HIV transmission and acquisition will spur creativity in addressing them, as well as establish expectations for effect sizes of various interventions. Behavioral and social science approaches are increasingly providing understanding of the interactions among biological, psychological, interpersonal, economic, and environmental factors that affect risk,

whether in the form of transmitting HIV to a seronegative person or acquiring HIV from a seropositive individual. Such studies have yielded impressive findings on factors, from cognitive to cultural, that are associated with risk behaviors. Appreciation of being personally at risk, perceived ability to modify that risk, and the skills, particularly interpersonal skills, to address the risk have been well studied and used as targets of intervention approaches. Other individual-level variables, such as depression and other serious mental disorder, have also been associated with risk, and stress has been associated with immunological parameters that, in theory, could affect risk.

The social setting also has considerable impact on risk. For example, it may do little good to teach women who are marginalized and oppressed to attempt to negotiate condom use with their husbands or primary partners, even when the partner is seropositive. Economic upheaval and extreme social disruption (e.g., through wars or civil unrest) promote violence conducive to HIV transmission and, through familial disintegration and destruction of health care infrastructure, create conditions where treatment for HIV/AIDS patients is severely hampered, if not impossible. Economic factors at both micro- (e.g., the cost of the drug to the individual) and macro- (e.g., policies that promote or dissuade large-scale cultivation of coca) levels certainly impinge on HIV risk behaviors. The geographic density of liquor outlets may be associated with STI and HIV risk. Even positive developments, such as the availability of simplified antiretroviral (ARV) dosing regimens, may have unintended consequences that affect risk.

Drugs of abuse vary across time and communities. Methamphetamine use, growing for several years now, continues to increase among young men and appears associated with increases in male-to-male risk behaviors. In Eastern Europe and parts of Asia, injecting drug use is associated with the majority of HIV transmission. While compounds of abuse change, it is possible to derive some general understanding of factors that predict risk associated with use of illicit drugs and alcohol and to use that understanding to guide programs and public health policy.

The NIH recognizes that understanding of HIV transmission and acquisition will require the skills of qualitative and quantitative researchers working from a variety of disciplines, and that development of a single, fully comprehensive model of risk that incorporates both individual-level and population-level perspectives is not a reasonable undertaking at this point. It is, nevertheless, necessary to develop a more comprehensive understanding to elucidate HIV/AIDS issues through approaches that integrate levels of analysis (e.g., individual, small group, social setting) and use a developmental or life-course perspective. Information from more comprehensive and integrative models of risk behavior will be useful to guide interventions as more refined understanding of risk factors and their interactions is developed. In particular, opportunities for intervention will be informed by inclusion of variables that are

potentially modifiable (e.g., cognitive, environmental, social setting, biomedical factors). That is, greater reliance on mediating rather than moderating variables will suggest avenues of intervention. Further, a greater understanding of the context and determinants of risk will allow more informed decisions to be made about the efficacy and effectiveness of research trials. Research could then be considered in light of whether changes resulting from an intervention reflect small changes in variables that account for or explain large amounts of risk behavior, or vice versa.

## INTERVENING IN HIV TRANSMISSION AND ACQUISITION

### PRIORITIES FOR FUTURE RESEARCH:

- **Develop and evaluate methods of intervening to reduce HIV acquisition and transmission associated with sexual behavior, using methods that recognize the contributions and interactions of individual, dyadic, group, community, and societal level (structural) variables, as well as the role of the environment and behavioral implications of technological advances in medicine (e.g., rapid HIV testing, medications to treat sexual dysfunction) and changes in medical practice (e.g., simplified dosing regimens, routine and universal testing).**
- **Develop and evaluate methods of intervening to reduce HIV acquisition and transmission associated with drug and alcohol use, using methods that recognize the contributions and interactions of individual, dyadic, group, community, and societal level variables, as well as the role of the environment and behavioral implications of technological advances in medicine (e.g., partial opiate agonist therapy) and changes in medical practice (e.g., directly observed therapy's integration with drug abuse treatment, increased attention to unique needs of women and ethnic/racial minorities).**

NIH intervention research priorities must continue to reflect the evolution of the HIV epidemic and advances in understanding the behavioral and social aspects of the disease. Despite the limited means of transmission, i.e., sexual, parenteral, and perinatal, social influences result in highly variable patterns of diffusion of the disease. As examples, in southern and eastern parts of Africa, the epidemic spreads primarily through heterosexual transmission and now is essentially generalized and affects nearly all the population. In those areas, women are disproportionately affected, and the disruption of family life wrought by AIDS is of crisis proportion. In other areas, such as Eastern Europe, the epidemic has a different appearance due to its primary spread through injecting drug use, heterosexual activity among drug users and their networks, and heterosexual activity of youth. MSM transmission predominates in some areas of South America and North America, while Asia's epidemic shows considerable variability across countries and regions. Domestically, the Centers for

Disease Control and Prevention (CDC), in an analysis of HIV diagnoses from 32 States reporting for 2003, indicated that the overall rate of HIV/AIDS diagnoses appears stable but sharp racial disparities remain. In those States, more than half of the diagnoses were among African Americans (13 percent of the population in the reporting States). Women, particularly Hispanic and African American women, were also disproportionately represented, with African American women having rates 18 times higher than those of white women. Even in communities of gay men where a great deal of prevention activity has taken place, data indicate that the early part of the 21st century was marked by increases in STIs and HIV cases. Another CDC report indicates that the United States has experienced a 17 percent rise in new HIV cases among homosexual men between 1999 and 2002, disproportionately affecting racial and ethnic minorities. While better surveillance may account for part of the increase in HIV cases, other reports on increases in risk behavior and STIs make it unlikely that the increases are primarily an artifact of improved detection. A research-based understanding of how social forces and individual behaviors interact can enhance efforts to prevent and treat HIV/AIDS.

An increased focus on studies that integrate biomedical and behavioral perspectives is needed. The development of more effective drug therapies and simplified dosing for combating HIV infection has raised behavioral questions with significant implications for HIV prevention, as treatment and prevention are inextricably linked from both biomedical and social/behavioral perspectives. Lack of adherence to treatment regimens could have devastating effects, not only on the individual level but on a population level if drug-resistant strains of HIV circulate widely as a consequence. In addition, as HIV-infected individuals experience improved health and a decline in detectable virus, they may believe that they are no longer capable of spreading the infection and return to or adopt unsafe practices. While it is intuitive that this optimism about the results of treatment precedes and causes subsequent risk behavior, empirical findings suggest that this might not necessarily or generally be the case. Rather, the treatment optimism often may follow risky sexual activity. More work needs to be done regarding how optimistic beliefs are developed, their relationship to behaviors after development, how to develop interventions in a context of optimism, and how to maintain community-level vigilance against HIV.

Another priority for integration of biomedical and behavioral perspectives is in youth who are or who will soon be sexually active. Reports of sexual activity, often coerced, among preteen and young teenage girls raise innumerable issues about the interactions of physiological and psychological maturation as they affect risk, decisionmaking and perceptions of self-efficacy, securing treatment for STIs, and other concerns. Gay youth similarly have unique concerns, and their responses to prevention messages are insufficiently understood. Certainly the cognitive, emotional, and physiologic development of young teenagers demands interventions distinct from those appropriate for older youth and young adults.

Behavioral and social research on the acceptability and use of biomedical interventions such as microbicides and vaccines is needed. The acceptability of such products is likely to vary greatly among communities, and studies will be needed to ensure that they are, when available, appropriately implemented. The behavioral and social effects of biomedical interventions also merit attention.

An emerging concern is increased sexual risk behavior associated with illicit use of medications to treat sexual dysfunction, especially when combined with methamphetamine or other stimulants already recognized as associated with HIV risk. Interventions to address that concern are sorely needed. On the other hand, buprenorphine, a partial opiate agonist, in combination with naloxone, shows considerable promise as a treatment for opiate abuse and is now available for use domestically but not in all international settings. Pharmacotherapies for cocaine and other abused stimulants have not yet been developed, but work toward those medications continues. As effective pharmacological and behavioral interventions for drugs of abuse continue to be developed and made available, there will be an attendant need to determine the effects of these treatments on HIV risk. Similarly, as interventions for alcohol abuse are refined and developed, their impact on HIV needs to be assessed, and interventions should be developed for the environments where alcohol use is a concern (e.g., bars, certain college settings, parties where underage drinking occurs).

Intervention research has shown that individual skills training and counseling can have an impact on HIV risk. Injecting drug users (IDUs) have been successfully taught to refrain from sharing injecting equipment and to clean their equipment, but efforts to shape their sexual behavior have met with only partial success, primarily in the form of reducing the number of partners. Individual counseling approaches have had an impact on risk behaviors of MSM, and group-based interventions have shown risk behavior reductions and reductions in STI incidence. Community-based peer interventions for both drug users and MSM have shown effects in this country and are being replicated abroad. Structural interventions to shape policies around condom use appear to have been successful in Thailand and the Dominican Republic, and more research is needed to develop and test structural and environmental manipulations that may reduce risk. Overall, while continued work needs to be done on individual and small-group interventions, there is a pressing need to address factors that are distal from the immediate decision to engage or not engage in risk. For example, programs that address stigma may have impacts on seropositive persons' engagement in care and subsequent transmission behaviors, and programs for the workplace or youth may have downstream effects of limiting exposure to risk situations or increasing cognitive and emotional capacity to avoid risk.

## **AMELIORATING THE CONSEQUENCES OF HIV INFECTION AND AIDS**

### **PRIORITIES FOR FUTURE RESEARCH:**

- **Support research on the interactions among factors that contribute to the cooccurrence of HIV/AIDS and other medical disorders (e.g., infectious diseases, substance abuse) and social problems (e.g., homelessness), and develop interventions to address the cooccurring conditions.**
- **Improve understanding of means to rectify disparities in consequences of and care for HIV infection through addressing the needs of various population subgroups and the stigma associated with HIV/AIDS, and through fostering integration of prevention and care services appropriate to both HIV-seropositive and HIV-seronegative persons.**

Many individuals who become HIV-infected also have, or are vulnerable to, a host of comorbid conditions, including other infectious diseases (e.g., hepatitis, STIs, and tuberculosis [TB]), drug and alcohol abuse, mental disorders, and homelessness. Further, stigma continues to be a concern of persons living with HIV and to interfere with quality care. As a result, it is important to develop and test the efficacy of interventions that simultaneously address the influences of multiple diagnoses, coinfections, and risks to improve quality of life and treatment outcomes. Interventions at the systems and individual levels are needed.

The NIH will continue to sponsor research on developing, implementing, and evaluating behavioral and social interventions to ameliorate the consequences of HIV infection and AIDS, to strengthen understanding of the impacts of HIV infection, and to improve services for those affected by HIV/AIDS. A human developmental framework is necessary to guide this research, along with the recognition of social and cultural factors and their variability across geographic settings. Research will be enhanced by increased linkages among researchers of varying disciplines, communities affected by HIV/AIDS, organizations responsible for HIV/AIDS care, and organizations addressing comorbid conditions.

## **LEVERAGING THE UTILITY OF EXISTING RESEARCH**

### **PRIORITIES FOR FUTURE RESEARCH:**

- **Test, refine, and apply findings from areas of research that are potentially relevant to HIV/AIDS issues, such as operations research, investigations of psychotherapy and behavior change with other medical conditions, management studies, family planning and reproductive health, behavioral economics, medical anthropology/sociology, and others, to determine the applicability of principles and procedures from those research areas and disciplines to HIV/AIDS.**

- **Integrate behavioral and social science expertise in the design and conduct of clinical trials and “strategy trials” of biomedical interventions so that behavioral and social aspects of biomedical interventions, such as acceptability and adherence, are included appropriately and adequately.**

In responding to the challenges that HIV presents to the scientific community, no area of science can long operate in isolation. Particular behavioral and social science disciplines need to integrate and use findings and approaches from other behavioral and social science areas, as well as from broader biomedical approaches. Conversely, broader biomedical areas need to be informed by the behavioral and social science approaches and findings. Examples of research advances arising from such collaborations are readily available. Approaches that integrated methods of behavioral epidemiology, infectious disease epidemiology, and molecular biology with principles of behavior change were used to ascertain the impacts of community-level interventions to reduce the use of dirty syringes. Another example is seen in research that combined knowledge of principles of peer influence with understanding about risk perception to create programs to use community influence and peers to affect sexual risk behavior among men who frequent bars and, in separate studies, among IDUs.

Untapped bodies of knowledge and methods of inquiry that could be profitably applied to HIV research remain. Some integrative work will be high risk, but with the possibility of substantially advancing knowledge if the high-risk activities prove fruitful. Principles of learning, information processing, and behavioral economics that govern other behaviors should, in theory, apply to HIV risk and coping. Operations studies that reveal how management decisions are made could be modified to address medical care delivery and prevention programming. The rich literature on relationship variables, therapist matching, and interpersonal processes in counseling and psychotherapy has scarcely been tapped for its implications for HIV prevention and care. Basic behavioral research on stimulus cues for drug abuse and sexual behavior has not been sufficiently considered for its implications for modification of cues in prevention work. As these examples suggest, methods used in studies not addressing HIV can often be adapted to HIV concerns. The NIH places a priority on utilizing a broad, transdisciplinary perspective in approaching HIV and, as part of that perspective, on recognizing that scientific principles derived from various areas of inquiry should be applicable in the context of HIV. Further, it is essential that HIV research not only test the applicability of principles from other areas, it should provide confirmatory or disconfirmatory evidence of the soundness of those principles, thereby advancing the scientific foundation of public health efforts.

Clinical trials and strategy trials, where interventions may follow one another, for HIV treatment and prevention are a particularly appropriate area for the integration



of behavioral, social, and biomedical approaches. Reliable and valid measurement of behavioral issues, such as adherence to the prescribed intervention, is essential for determining efficacy. Social factors, attitudinal variables, norms, and economic influences may have roles in other biomedical studies, and these may need to be addressed. HIV research is revealing that behavioral, social, and biomedical approaches are often simply various ways to investigate the same phenomenon, albeit at different levels of analysis, and understanding HIV requires analysis at the various relevant levels.

Because biomedical, behavioral, and social approaches are not always distinct, complex design and statistical approaches are needed to concurrently address multiple levels of analysis. One of the difficulties encountered in analyzing current research at the behavioral and social levels is the lack of highly powered studies with both behavioral and biomedical (such as HIV seroincidence) outcomes. Creating databases that combine information from many studies in order to improve statistical power would be one approach to fostering integration of biomedical, behavioral, and social perspectives. Such large-scale databases would not only detect significant interactions between and within a variety of behavioral domains but also identify the role of behavioral actions as mediators and moderators of HIV-related biological outcomes. These shared databases also will allow the development statistical methods to prioritize key interactions for prevention and treatment interventions for future investigation.



## SCIENTIFIC OBJECTIVES AND STRATEGIES

### OBJECTIVE - A:

- **Develop, evaluate, and advance prevention interventions: Support research to develop, evaluate, and diffuse effective behavioral, social, environmental, and economic interventions to prevent HIV transmission and acquisition by reducing HIV-related risk behaviors and increasing protective behaviors. Both domestic and international interventions should address the social and cultural contexts within which risks occur (e.g., social class, gender, race, age, education, and ethnicity) and attend to ethical issues.**

### STRATEGIES:

- Develop and evaluate the efficacy, effectiveness, and cost-effectiveness of demographically and culturally appropriate behavioral and social interventions in different domestic and international settings and populations to reduce high-risk HIV-related sexual and drug-use behaviors and HIV transmission.
- Translate and apply basic behavioral and social science research to optimize the development of innovative and effective intervention strategies.

### Populations and Contexts

- Develop and test interventions targeted at HIV-infected persons to reduce their risky sexual and drug-use behaviors.
- Support intervention research that addresses the impact of alcohol and/or drugs on sexual encounters that may contribute to HIV transmission and acquisition.
- Continue development of interventions targeting at-risk populations (e.g., IDUs, other drug users, partners of drug users, street children, and MSM), with particular emphasis on drug-use and sex-related risks.
- Continue development of interventions for persons with multiple mental and physical disorders.
- Support domestic and international intervention research on the HIV prevention role of programs designed to enhance healthy sexual development and protective behaviors (including avoidance of too-early or nonconsensual sex, abstinence from unsafe sexual behavior, and access to and use of barrier methods) throughout one's lifetime.
- Support interventions for populations that are currently at low risk or that perceive themselves to be at low risk for HIV infection, but that may be susceptible to engaging in high-risk behaviors (e.g., non-sexually active, non-

drug-using adolescents; subpopulations of heterosexual men and women; and certain middle-aged and older populations).

- Support intervention research that addresses important contextual risk factors for disproportionately affected groups that continue to demonstrate high-risk behaviors. This research also should identify which public health applications most effectively attend to cultural contexts.
- Develop, test, and evaluate interventions that target individuals both within prisons and returning to society from the prison system; strategies include increasing access to education, information, therapeutic care, substance abuse treatment, prevention services, and clinical trials.
- Support the capacity to develop rapidly domestic and international intervention studies in response to changes in the epidemic.

#### Effectiveness

- Develop, test, and evaluate interventions that target a range or combination of levels of social organization (i.e., individual, dyad, family, network, community, institution, and society) and that examine how these levels interact to affect HIV risk and protective behavior and HIV transmission in different cultural contexts.
- Support research to increase the effectiveness of family planning interventions and treatments for drug abuse, mental disorder, and alcohol abuse as strategies of HIV prevention.
- Conduct studies to identify key components of efficacious interventions to facilitate transfer, adaptation, and application of them.
- Support research in the United States and abroad to improve the transfer of effective HIV interventions among communities, particularly research on the adoption and adaptation of efficacious HIV interventions by communities (including studies of diffusion processes and the exchange of knowledge between service providers and researchers); this research includes study of the maintenance of effective interventions and assessment of the generalizability of interventions with diverse populations.
- Evaluate novel interventions identified as high priority by HIV community planning groups and other service providers.
- Support research on the long-term impact of HIV prevention interventions on individuals and communities (i.e., 5 or more years postintervention).

## Systems

- Support research to understand and improve the organization, financing, management, access, delivery, cost-effectiveness, and cost-utility of health care (including care for substance abuse and other psychiatric disorders), family planning, and other social services that reduce HIV risk behaviors and HIV transmission.
- Support research to understand and improve prevention services' linkages, coordination, and integration with primary medical and dental care; drug, alcohol, and mental health treatment; STI treatment; reproductive health and family planning services; services for orphans and vulnerable children, and other social services.
- Support research on integrating HIV prevention interventions into drug addiction treatment settings, with emphasis on behavioral treatments, alone or in combination with pharmacotherapies, for both HIV-positive and HIV-negative drug users.
- Support intervention research on strategies for improving the willingness of communities to adopt and sustain primary prevention interventions.

## Methods

- Design and test behavioral interventions for relevant populations to increase recruitment, retention, and adherence to protocols for HIV prevention research, including trials studying prophylactic vaccines, microbicides, and other biomedical prevention methods.
- Encourage, where appropriate, the use of quasi-experimental designs and the evaluation of natural experiments in domestic and international HIV intervention research.
- Support behavioral intervention studies that include HIV seroincidence data and other biologic markers as outcome measures.

## OBJECTIVE - B:

**Conduct basic social and behavioral research on factors influencing HIV risk behaviors and on the consequences of HIV disease: Support basic social and behavioral research to strengthen understanding of the determinants, processes, and cultural and contextual issues influencing HIV-related risk and protective behaviors and the consequences and impact of HIV disease, including treatment for and management of HIV infection. This includes domestic and international research that examines the societal, community, organizational, social network, dyadic, and individual barriers to and facilitators of the adoption and utilization of effective preventive and treatment interventions across the life course.**

## STRATEGIES:

### Continuing Critical Areas

- Conduct basic research to understand better the impact of HIV therapeutic regimens on adherence to treatment for HIV and cooccurring infections, sexual risk behaviors, drug-related risk behaviors, and psychosocial adaptation (i.e., improved quality of life).
- Examine brain mechanisms that underlie HIV risk behaviors, such as how the brain processes and uses representations of long-term consequences of behavioral choices to guide immediate behaviors.
- Develop new models of behavioral change that integrate biological, psychological, and social perspectives to explain and predict the adoption and maintenance of HIV risk and HIV protective behaviors among vulnerable individuals and understudied groups, both domestically and internationally.
- Support theory-building studies developed in the context of HIV prevention research.
- Support research that can more closely monitor the HIV/AIDS epidemic and associated risk behaviors so that emerging needs for basic behavioral and intervention research can be identified.

### Consequences

- Support research on the decisionmaking processes and behaviors of health care workers regarding the offering of HIV counseling, testing, and other prevention services, as well as the prescription of HIV disease treatments, to those in need of HIV services and care.
- Conduct research concerning the health and life course of children, including orphans, affected by HIV. This research should include early identification

and assessment of affected children for physical, psychological, and social consequences.

- Identify the neurobiological, behavioral, cognitive, social, and economic consequences of HIV disease for HIV-seropositive individuals (including children), their support systems (e.g., partners, family members, and other caregivers), health care systems, and communities.
- Support research on the economic and social implications for retired and older individuals who provide support and care to younger family members or friends with HIV/AIDS and their dependents.
- Support behavioral research to study end-of-life transition strategies for patients with HIV/AIDS and their caregivers.
- Support interdisciplinary research, involving behavioral and biomedical scientists, to determine the relationships among stress, mood disorders, immune system functioning, and HIV infection, and to examine the psychosocial and physiological factors affecting those relationships.
- Support studies on animal models of behavior and behavioral change relevant to HIV infection and prevention; in particular, conduct behavioral neuroscience and neuropsychological research to determine the brain/behavior changes associated with exposure to HIV, the effects of HIV exposure on social behaviors (e.g., mother-infant attachment and peer interactions), and behavioral changes in relation to comorbidities of HIV and substance use and addiction.

### Prevention

- Study the acquisition and maintenance of HIV-related risk and protective behaviors associated with HIV transmission or progression in specific social and cultural contexts, such as the sexual dyad, peer groups, social and substance-using networks, families, and communities. This would include studies of HIV risk, transmission, and progression as related to cultural norms that affect disempowerment of and violence toward women.
- Study how HIV risk might change over time as a function of developmental and life-course events, such as adolescence, childbearing, marriage or entry into other committed partnership, divorce and separation, and aging.
- Conduct research on decisionmaking processes that relate to sexual and drug-related risk-taking across the life course (e.g., individual and dyadic decision processes concerning whether and under what circumstances to have sexual intercourse; risk assessment of self and partner; the weighing of pregnancy prevention, HIV prevention, and relationship goals in choosing to use a condom and/or other method) and decisionmaking processes related to sharing

needles or other drug paraphernalia and having sex with someone who may be infected.

- Support multidisciplinary research that investigates the biobehavioral and sociobehavioral determinants of sexuality, including processes of sexual and gender identity formation, as they relate to HIV risk.
- Conduct research on partner selection and relationship dynamics, including how partner choice, partner formation, relationship development, and partner stability change over the life course and affect HIV risk and HIV-related behavior; studies should examine psychological, cultural, and social factors that influence these phenomena. Interactions of alcohol/drug use with partner selection and demographic trends in partnering, as related to HIV risk, should also be addressed.
- Support multidisciplinary research that investigates biobehavioral and sociobehavioral determinants of injecting drug use and the transition from noninjecting to injecting drug use as they relate to HIV transmission; such research may also include studies that investigate the relationship between any drug use and sexual risk behaviors.
- Conduct research on individual social and cultural differences in human sexuality that have an impact on the sexual transmission of HIV; such research may include studies that examine how sexual behavior is affected by substance use and abuse, sexual abuse or coercion, developmental processes, and the formation and dissolution of intimate relationships.
- Study the social, structural, cultural, and demographic factors (e.g., socioeconomic status, marital status, ethnicity, sexual identification, age, and gender) that influence HIV-related behavior.
- Support research to understand how and whether communities engage in HIV preventive interventions, including studies to determine how to better ensure the use of prevention research by communities and public health entities in the United States and abroad.
- Support research that investigates the impact of laws and policies on behaviors associated with HIV transmission and acquisition.
- Conduct research that identifies the social and behavioral factors affecting recruitment, retention, and adherence to prevention and treatment interventions, including clinical trials of HIV-related vaccines, microbicides, and therapeutics.
- Support behavioral and social research on the acceptability and use of biomedical HIV prevention methods (e.g., condoms, microbicides, and vaccines).



- Support basic and preintervention research on behavior modification and maintenance of new behavioral patterns for developing prevention and intervention strategies.
- Support behavioral surveillance research that measures changes in norms and attitudes regarding behaviors associated with HIV transmission and acquisition.
- Support research to identify how alcohol use (e.g., binge drinking trends) affects HIV risk among selected age groups.

## **OBJECTIVE - C:**

**Conduct treatment, health, and social services research for people infected and affected by HIV: Support research into the development, evaluation, diffusion, and adoption of strategies to increase early identification of HIV infection; to improve treatment adherence; and to prevent or minimize the negative physical, psychological, cognitive, and social consequences of HIV infection, including stigmatization of persons with or at risk for HIV infection. Support research strategies for promoting effective health care utilization among all persons with HIV infection and for promoting modifications in the health care delivery system to develop more effective, socially appropriate, and culturally sensitive methods to better serve treatment needs of infected populations, both domestically and internationally.**

## **STRATEGIES:**

### Treatment and Care

- Develop and test interventions to modify the practice behaviors and decisionmaking processes of health care providers to improve the quality of screening, counseling, and treatment services for HIV-positive persons and persons at risk for HIV infection.
- Support research on adherence to treatment regimens, including studies on communication techniques to improve shared decisionmaking between health care providers and HIV-infected individuals, issues such as how and when to initiate, interrupt, or cease therapy, and behavioral strategies to manage symptoms secondary to treatment protocols.
- Promote research to identify and remove barriers to effective health care utilization among persons with or at risk of HIV infection, including barriers associated with access, engagement, followup, and adherence to health and social services across the care continuum (e.g., early identification of HIV infection, testing and counseling, health care-seeking behavior, adherence, case management, and home/hospice care) and across the life course (i.e., from childhood to old age).
- Develop and test interventions to increase recruitment, adherence, and retention in HIV/AIDS clinical trials and care by HIV-infected persons from all vulnerable populations, with special attention to developmental and life-course issues.
- Support health services research and evaluation research to determine the impact of changes in the health care delivery system on HIV/AIDS care.
- Support research to foster more effective participation in treatment planning, decisionmaking, and formulating advance directives by patients with HIV and their families.

### Biopsychosocial Consequences

- Develop and evaluate interventions to prevent the adverse psychological and social consequences of HIV infection and to assist HIV-affected populations in coping with HIV infections, maintaining quality of life, and avoiding engagement in HIV-related risk behaviors.
- Test interventions to address the neuropsychological, neurodevelopmental, and psychiatric sequelae of HIV infection.
- Develop and evaluate interventions to minimize the impact of stigmatization on HIV-infected persons, including on their decisions regarding treatment and quality of life.
- Test interventions designed to support formal and informal caregivers and family members of HIV-infected persons in order to prevent, for example, depression and burnout.
- Support research to enhance the quality of life and minimize the impact of pain, fatigue, physical symptoms, and treatment side effects and to integrate effective palliative care throughout the course of treatment for all people living with HIV and AIDS.

**STRATEGIES:**

**OBJECTIVE - D:**

**Improve the quality of behavioral and social science methodology in HIV research: Support research to advance innovative quantitative and qualitative methodologies to enhance behavioral and social science on HIV prevention and care, and to address pressing ethical issues in the conduct of such research.**

Measurement

- Develop improved methodologies—including methods for obtaining and validating self-report data, culturally appropriate standardization of measurement tools for surveys, and the measurement of change over time—based on an assessment of the current status of qualitative and quantitative methodologies for studying behavioral and social factors associated with HIV and AIDS.
- Develop and strengthen research instruments that are culturally and linguistically appropriate for subpopulations (e.g., HIV-infected children, the elderly, and prisoners) and that reflect age-appropriate concerns.
- Develop and refine techniques for measuring social networks associated with HIV transmission.
- Support research to determine under what circumstances each of the following outcome measures—alone or in combination—is appropriate to use: self-report measures, HIV infection, and other disease outcomes such as other STIs and blood-borne diseases.
- Develop improved qualitative approaches to theory building and to measurement of HIV-related behaviors, behavioral change, and factors that influence behavior and behavioral change.
- Develop improved approaches to formulate, integrate, and analyze theories founded on qualitative and quantitative observations.
- Develop and refine outcome measures and indicators appropriate for the evaluation of social policy and the societal impact of HIV prevention and treatment interventions.

Modeling

- Develop and refine mathematical models for linking behavioral change interventions with a reduction in HIV transmission at different levels of seroprevalence.
- Improve methods for forecasting and modeling AIDS caseloads, health care needs, and health care utilization under different treatment and survival

scenarios and for forecasting and modeling prevention services needs.

### Design and Statistical Analysis

- Develop improved sampling strategies for subpopulations (e.g., children, homeless persons, drug users, the elderly, and gay men of color).
- Develop improved and innovative methods and techniques for conducting and analyzing longitudinal studies of HIV-vulnerable and HIV-infected populations, including improved participant retention strategies; statistical methods for dealing with participant attrition, missing data, and nonnormal distributions; and methods for measuring and analyzing nonlinear patterns of behavior change.
- Foster the development and dissemination of design alternatives to the randomized controlled trial that permit cost-effective evaluation of intervention strategies at the individual, group, and community levels.
- Foster the development, maintenance, and use of shared databases that will enhance the ability to identify and detect significant interactions between and within a variety of behavioral domains and also to identify the role of behavioral actions as mediators of biological outcomes of importance in HIV research.

### Ethics and Other Issues

- Evaluate the effects of legal and ethical constraints on methods of HIV research and service delivery, particularly among vulnerable or special populations.
- Develop and refine research techniques to advance multisite, intercultural, and international studies.
- Encourage secondary data analysis; develop approaches to protect and document confidentiality.
- Develop and evaluate mechanisms for dissemination of behavioral research findings to the HIV/AIDS research and service communities and for receiving and evaluating community or constituent feedback.



FY 2007 OAR  
Planning Group for  
Behavioral and Social Science





## **FY 2007 BEHAVIORAL AND SOCIAL SCIENCE PLANNING GROUP**

### **Non-NIH Participants**

**David D. Celentano, Sc.D., M.H.S., Co-Chair**  
Professor  
Director, Infectious Disease Epidemiology  
Johns Hopkins Bloomberg School of Public Health

**Cynthia Gomez, Ph.D.**  
Co-Director  
Center for AIDS Prevention Studies  
AIDS Research Institute  
University of California, San Francisco

**Kathleen M. MacQueen, Ph.D., M.P.H.**  
Senior Scientist  
Family Health International

**Kathleen J. Sikkema, Ph.D.**  
Associate Professor  
Department of Psychiatry  
Yale University School of Medicine

**Claire E. Sterk, Ph.D.**  
Professor and Chair  
Department of Behavioral Sciences and  
Health Education  
Rollins School of Public Health  
Emory University

**Darrell P. Wheeler, Ph.D., M.P.H.**  
Assistant Professor  
School of Social Work  
Hunter College, City University of New York

**Eric R. Wright, Ph.D.**  
Associate Professor  
Department of Sociology  
Indiana University-Purdue University, Indianapolis

### **NIH Participants**

**William C. Grace, Ph.D., Co-Chair**  
Coordinator  
Behavioral and Social Science Program  
Office of AIDS Research  
Office of the Director, NIH  
U.S. Department of Health and Human Services

**Kendall Bryant, Ph.D.**  
Coordinator, Alcohol and AIDS Research  
National Institute on Alcohol Abuse and Alcoholism, NIH  
U.S. Department of Health and Human Services

**Paul Gaist, Ph.D., M.P.H.**  
Health Scientist Administrator  
Behavioral and Social Science Research  
Office of AIDS Research  
Office of the Director, NIH  
U.S. Department of Health and Human Services

**Christopher M. Gordon, Ph.D.**  
Health Scientist Administrator  
Division of AIDS and Health and Behavior Research  
National Institute of Mental Health, NIH  
U.S. Department of Health and Human Services

**Martha L. Hare, Ph.D., R.N.**  
Program Director  
National Institute of Nursing Research, NIH  
U.S. Department of Health and Human Services

**Jeanne McDermott, Ph.D., C.N.M., M.P.H.**  
Program Officer  
Division of International Training and Research  
John E. Fogarty International Center, NIH  
U.S. Department of Health and Human Services

**Susan E. Newcomer, Ph.D.**

Statistician

Demographic and Behavioral Sciences Branch

Center for Population Research

National Institute of Child Health and Human

Development, NIH

U.S. Department of Health and Human Services

**Jacques Normand, Ph.D.**

Director of AIDS Research

National Institute on Drug Abuse, NIH

U.S. Department of Health and Human Services

**Thandi Onami, Ph.D.**

AAAS Fellow

Division of International Training and Research

John E. Fogarty International Center, NIH

U.S. Department of Health and Human Services

**Monica S. Ruiz, Ph.D., M.P.H.**

Behavioral Scientist/Health Scientist Administrator

Prevention Sciences Branch

Division of AIDS

National Institute of Allergy and Infectious Diseases, NIH

U.S. Department of Health and Human Services